

2021-2022 Lived Experience Panel



Priorities for Person and Caregiver Relevant Outcomes in Dementia Intervention Research

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Executive Summary

What is the Lived Experience Panel?

The National Institute on Aging (NIA) Imbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory and Alzheimer's Association convened a Lived Experience Panel. This panel includes 12 people living with dementia and care partners of people living with dementia. The purpose of the Lived Experience Panel is to have members share their thoughts and experiences on a variety of specific topics to help inform future dementia research. The Lived Experience Panel met twice in April 2021 with the IMPACT Patient and Caregiver Relevant Outcomes Core. This report describes the discussion topics and findings of these meetings.

Discussion Topic 1: Important study outcomes

The first discussion was about the research study outcomes that are important to people living with dementia and their care partners. Panel members talked about many shortcomings in the way the US health care system currently treats people living with dementia. Panel members also described social and emotional needs at diagnosis and as dementia progresses.

Discussion Topic 2: "Reducing hospitalizations" and "living life according to personal preferences"

During the second discussion, panel members gave input on two outcomes often studied by the IMPACT Collaboratory: reducing hospitalizations and "living life according to personal preferences".

Reducing Hospitalizations - Nearly all panel members thought that reducing hospitalizations was very important but that it is not always better to have fewer hospitalizations. They thought that hospitalizations can provide necessary medical care. Panel members also described many potential harms of hospital stays. They also said that racism can make hospital stays harder for people of color.

Living life according to personal preferences - Panel members thought that people living with dementia should be as independent as possible and be able to choose what happens in their daily lives and in their health care. They also said that health and safety need to be balanced with independence and choice. This can create tension between the person living with dementia and their care partner.

Reflections on the Lived Experience Panel meetings

The panel described outcomes that are important to people living with dementia and their care partners. These are not always the same outcomes studied by IMPACT investigators. It is important the panel continues to meet so that IMPACT research remains focused on person and caregiver relevant outcomes. The panel should also discuss other important topics, such as research ethics and health equity.



About NIA IMPACT

The [National Institute on Aging \(NIA\) Imbedded Pragmatic AD/ADRD Clinical Trials \(IMPACT\) Collaboratory](#) (U54AG063546) was established in 2019 to build the nation's capacity to conduct embedded [pragmatic clinical trials](#) (ePCTs) of non-pharmacologic interventions within health care systems to improve the care of people living with Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD) and their care partners. The IMPACT Collaboratory does this through a coordinated effort between [IMPACT's leadership](#) and topic-focused [Cores and Teams](#) to:

- Develop and disseminate best practice research methods
- Support the design and conduct of embedded pragmatic clinical trials (ePCTs), including pilot studies
- Build investigator capacity through training and knowledge generation
- Catalyze collaboration among stakeholders, healthcare providers, and investigators
- Ensure research includes culturally-tailored interventions and people from diverse and under-represented backgrounds

Ten topic-specific [Cores and Teams](#) work with the [Administrative Core](#) and funded investigators to accomplish the mission of the IMPACT Collaboratory. These [Cores and Teams](#) are comprised of experts in their fields who work together under the direction of IMPACT leadership to develop and share best practice research methods, support the design and conduct of ePCTs, and provide guidance to IMPACT members and investigators.

About the Alzheimer's Association

The [Alzheimer's Association](#) is the leading voluntary health organization in Alzheimer's care, support, and research. Its mission is to lead the way to end Alzheimer's and all other dementias by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support. The Alzheimer's Association vision is a world without Alzheimer's and all other dementias.

About the Lived Experience Panel

The [Lived Experience Panel](#) is a group of nine to twelve people living with dementia or caring for people living with dementia who help inform research priorities and challenges by sharing their thoughts and experiences with researchers from IMPACT's Cores and Teams in periodic panel meetings. The Lived Experience Panel meets 4 times a year, covering different topics that may span more than one meeting. Generally, each topic area is introduced with a simple presentation by IMPACT research team members, followed by a discussion with panel members to capture their thoughts and feedback to the topic presented.

The diverse members participate in panel activities for one to two years. New panel members are added as previous panel members complete their participation period.



Members were identified through an outreach and application review process, and the Lived Experience Panel was first convened in Spring 2021. The first panel is composed of eleven people reflecting various perspectives, including:

- Four people with a documented diagnosis of early stage Alzheimer's, Mild Cognitive Impairment, or other early stage dementia
- Three care partners/caregivers representing their own experience caring for a person living with dementia
- Four care partners/caregivers representing the perspective of one or more people living with dementia with middle or late stage dementia or who are deceased

The types of dementia represented by panel members were: Alzheimer's (6), Vascular dementia (2), Dementia (not otherwise specified) (1), Lewy Body dementia (1), Parkinson's disease (1), Frontotemporal dementia (2), Mild cognitive impairment (1). Some participants represented more than one type of dementia. The Lived Experience Panel included people with the following characteristics and identities: Female (9), Male (2), Asian-American (1), Black or African-American (3), White (7), Latina (2), and LGBTQ+ (2).

The Lived Experience Panel Report

Summary reports are written by the IMPACT Core or Team that facilitates the meeting/s for each topic area and are reviewed by members of the Lived Experience Panel before being published and shared with the public. All reports are available on the [IMPACT website](#).

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Introduction to this Report

This report summarizes the discussion and insights gained in the two Lived Experience Panel meetings that featured conversations about outcomes important to people living with dementia and their care partners. The meetings were held over Zoom on April 15, 2021 and April 22, 2021. [Antonia V. Bennett, PhD](#), [Laura C. Hanson, MD, PhD](#), and [Sheryl Zimmerman, PhD](#), from IMPACT's [Patient and Caregiver Relevant Outcome \(PCRO\) Core](#) coordinated the development of the discussion topics and led the discussions. The meeting agenda included:

- An overview of the kinds of research being conducted by IMPACT investigators and the goals for the Lived Experience Panel meetings
- Topic 1. Discussion of changes needed to improve the experience of people living with dementia and their care partners
- Topic 2. Discussion of two outcomes often studied by IMPACT researchers, including: 1) reducing hospitalizations and 2) increasing the degree to which people living with dementia can live life according to their personal preferences

Overview: What kinds of research studies are conducted by IMPACT? What will our Lived Experience Panel discussions be about?

This introductory discussion provided panel members with information to help them understand the IMPACT Collaboratory and plan for future discussions. We began by explaining that IMPACT studies test new ways to improve the care and well-being of people with dementia and their care partners. We clarified that IMPACT studies do not test new drugs or procedures for preventing or treating dementia. Next, we introduced two key terms: “interventions” and “outcomes”, and presented four examples of each term. This is one example:

In a research study, we test an **intervention** to see if it improves an **outcome**.

Example: A new exercise program is tested to see if it reduces falls and fall-related injuries.

Intervention = new exercise program

Outcome = percent of people who have a fall and a fall-related injury

Panel members asked questions to make sure they understood. We closed this portion of the meeting by reminding the panel that the goal of the first two meetings was to learn about the kinds of outcomes that are important to the Lived Experience Panel members.

Responses

Panel members responded with clarifying questions, which Drs. Hanson and Zimmerman answered.



Discussion Topic 1: What would you like to change about your experience with dementia or dementia caregiving?

The purpose of this discussion topic was to identify research study outcomes that are important to people living with dementia and their care partners. This discussion was framed using the “miracle question”, that asks individuals to think about what would have changed if a miracle had happened. The prompt was as follows:

“Research interventions can’t make dementia go away, but they CAN make living with dementia and its effects on everyday living better. We’d like to use the rest of our time today to hear from YOU about what outcomes matter the most. To do this, we’d like each of you think about what would be different in your life if a miracle occurred to make your life better (other than that a miracle can’t make dementia go away). Let’s imagine that tonight, while you’re sleeping, a miracle happens that solves a problem you’ve been having related to dementia and its effect on your daily life. What would be different when you woke up to make you realize a miracle had happened?”

We encouraged Lived Experience Panel members to describe the issues in terms of a problem that had changed, instead of describing a solution, because the purpose of the discussion was to identify outcomes important to people living with dementia and caregivers.

Response Overview

Lived Experience Panel members shared a range of potential outcomes that – if improved – would improve their experience living with dementia. These potential outcomes were mostly about to health care and social and emotional needs.

First, members of the panel identified a number of **gaps and shortcomings** in the way the US health care system currently provides health care for people living with dementia. These gaps in care quality were experienced at multiple time points, including: 1) time of diagnosis, 2) when receiving routine medical care, 3) during hospitalizations, and 4) when additional support is needed, such as respite care or admission into long-term care. The gaps created stress, extra work, and additional expenses for the people living with dementia and their care partners. The lack of cultural competence in clinical care teams and the lack of translators and translated documents was a problem at many points of care. Inadequate health insurance coverage or lack of insurance greatly limited people’s access to health care and support services.

Needs Related to Health Care

Lived Experience Panel members identified the following needs related to health care:

- Receiving more informational support at the time of diagnosis
- Greater forewarning about problems and needs that are likely to occur



- Clinicians who are experienced in working with people living with dementia, including primary care clinicians and clinicians providing other types of routine care
- Clinicians and care teams who are culturally competent, have cultural humility, and provide care that is culturally responsive
- Interpreters and written materials in the person's preferred language
- Less difficulty finding medical care and nursing home openings, especially in rural areas and for particular types of dementia
- Access to respite care and companionship
- Fewer out-of-pocket costs of receiving care and meeting all the needs of people living with dementia, especially for people who are uninsured, undocumented, or without family wealth

Social and Emotional Needs

Panel members identified the following unmet needs related to the social and emotional aspects of their experience:

- To feel less alone and anxious at the time of diagnosis
- Ability to continue doing normal and valued activities (e.g., reading, talking with friends, working)
- Less sadness and boredom
- To not be perceived differently by others once they learn the diagnosis
- Greater social inclusion and respect
- To have friends and acquaintances be more familiar with how to maintain friendships and day-to-day social interactions with people living with dementia
- More attention on what people living with dementia can do and to focus on the positive, as it can be damaging to people living with dementia when the focus is on deficiencies or when negative attitudes about dementia are perpetuated
- Reduced burden for family care partners in providing care over multiple years
- Less family stress and conflict, as stress and conflict can arise from changes in roles, feelings of grief and loss, not understanding dementia, and family members not helping or becoming isolated

Recommended outcome domains follow from each of these responses. For example, research should be designed to improve health care outcomes of care partner preparedness, access to dementia-trained clinicians and specialty services, culturally competent care, and financial burden of dementia care. Outcome domains of anxiety, depression, social engagement, social stigma, and caregiver stress are endorsed as highly relevant to the lived experience of this condition and should be a focus for future intervention research.

Panel members conveyed that fear, sadness, boredom, and isolation were common, as were family stress and conflict. Although not asked to define interventions, during the discussion,



members of the panel identified a number of ways the social and emotional needs of people living with dementia and their care partners could be met, including:

- Participating in society through friendships, activities, working, and volunteering
- Identifying ways to limit burden on family members and maintain independence
- Increasing the public's understanding of what people living with dementia can do and how to make social interactions and activities inclusive
- Providing greater support and guidance to families

Discussion Topic 2: Reflections on two outcomes often studied by the IMPACT Collaboratory; reducing hospitalizations, and living life according to personal preferences

Panel members to share their thoughts about two outcomes often studied by investigators working with the IMPACT Collaboratory: **reducing hospitalizations** and **“living life according to personal preferences”**. The goal was to learn about how people living with dementia and their care partners view these outcomes, including their importance to the lived experience of people living with dementia and any specific details about these outcomes that researchers should consider when they include them in research studies.

The first outcome, **reducing hospitalizations**, was chosen because it has been used as an outcome measure in prior pragmatic and efficacy clinical trials enrolling people with advanced dementia and related dementias. Data collection about hospitalizations can be done within pragmatic trials, and evidence suggests that this outcome is important for the lived experience of people living with dementia. People with dementia experience hospitalizations more frequently than those without dementia, yet they may benefit less from hospitalization and may experience unintended harms more often than people without dementia. Additionally, hospitalization is costly for people with dementia, their families, and for the health care system.

The second outcome discussed was **“living life according to personal preferences”**, which was chosen because evidence shows it is important given the nature and length of advanced dementia and advanced dementia-related diseases. While this is less pragmatic to measure because it may require people living with dementia and/or their care partners to complete questionnaires, it is an example of an outcome highly relevant to the autonomy and dignity of the person living with dementia. The importance of preference-driven activity and care is fundamental to many efforts to improve dementia care and services. It is relevant to a range of activities, from advance care planning to person-centered care plans in nursing facilities that individualize daily schedules and personal care. This outcome was presented as:

“The person with dementia being able to live life according to personal preferences (e.g., doing their favorite activities, choosing their own bedtime, and going outside when they want).”

For each outcome, panel members were asked:



“How important is this outcome to you? Is it very important, somewhat important, or not important? Why?”

Responses Related to Reducing Hospitalizations

Reducing hospitalizations was rated as very important by nearly all Lived Experience Panel members. While they recognized that hospitalizations can be important to address acute illness needs, they explained their rating with a range of concerns about the potential harms of hospital stays. It was widely agreed that hospitalizations are different from emergency department visits, and emergency department visits have other benefits and harms.

Panel members described many **challenges and harms of hospitalizations**. For people of color, the experience of racism makes hospitalizations more burdensome. Staying at the hospital can be confusing and upsetting for people who don't understand or can't remember why they are there, and this can lead to decline in function. Hospitals can be a source of infections. The financial burden of hospital visits can be substantial. The burden to care partners can be high. Some care partners will stay at the hospital the entire time to make sure the person living with dementia is getting good care and to provide support to their relative. This is especially challenging when hospital stays last multiple weeks.

The benefits of hospitalizations described by panel members included access to necessary medical care and symptom management and a sense of relief and safety for some people living with dementia and their care partners. However, the perceived benefit is affected by the reason for hospitalization and the potential for hospital care to lead to improved health outcomes. Therefore, reducing unnecessary hospitalizations is very important; and, because of the valuable benefits of some hospitalizations, reducing overall hospitalizations should not always be considered a desired outcome.

Responses Related to “living life according to personal preferences”

Living life according to personal preferences was rated as very important by most panel members but rated as somewhat or not important by others. Reasons for individual ratings were varied. Panel members acknowledged that there are sometimes tensions between preferences, such as a tension between preserving independence and the individual rights of the people living with dementia, while also ensuring their safety. The ability to drive a car was shared as an example of this tension. Some care partners noted that they can be perceived as “the person who restricted their activities,” creating relationship tension. People living with dementia value accommodations by friends and family that permit them to continue participation in favorite activities. Participants also discussed the emerging value of video-conferencing as a result of the COVID pandemic, allowing for advocacy group meetings, support group meetings, or visits with loved ones without having to seek transportation.

In general, members of the Lived Experience Panel acknowledged the importance of autonomy and preference-driven activity or care but recommended it be seen in the context of other concerns.



Outcomes that are Important, Yet Complex

The discussions about the importance of “reducing hospitalizations” and “the person with dementia being able to live life according to personal preferences” revealed most members of the Lived Experience Panel endorsed these outcomes as important, yet urged consideration of their complexity. In each of these topics there is a tension between different aspects of well-being. The appropriate balancing of these aspects also changes over time. Investigators should consider these complexities when designing research studies about these topics.

Reflections on the Lived Experience Panel Meetings

For some panel members who were asked to serve as a “proxy” by representing the perspective of someone living with middle- or late-stage dementia or who was deceased, it was challenging to provide input from the perspective of a proxy. They recognized that their perspective on what the people living with dementia may have wanted or thought was filtered through their own lens.

It is clear that the Lived Experience Panel is able to articulate important outcomes that may not be wholly consistent with those studied by IMPACT investigators. Therefore, it is important that they continue to be engaged to ensure that IMPACT research remains focused on outcomes relevant to people living with dementia and their care partners and to address other important topics (e.g., research ethics and health equity in dementia care).

Feedback from the Lived Experience Panel on this Summary Report

This draft report was discussed with the Lived Experience Panel on July 15, 2021. The discussion included suggested revisions and clarifications, as well as additional comments on each topic. The draft report was revised to reflect this discussion and was shared with panel members for any final comments.

Conclusions

This first series of meetings with the Lived Experience Panel oriented members to the types of outcomes studied by IMPACT, discussed outcomes relevant to people living with dementia and their caregivers, and discussed the nuances of two complex outcomes commonly assessed in IMPACT studies. The panel provided valuable insights that will inform the design of IMPACT studies.

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